Original Article

Patient Characteristics Associated With Prognostic Awareness: A Study of a Canadian Palliative Care Population Using the InterRAI Palliative Care Instrument

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Abstract

Context. Awareness of their medical prognosis enables terminally ill patients to make decisions on treatments and end-of-life care/planning, and to reach acceptance. Yet, many patients receiving palliative care (PC) are unaware of their prognosis, even when death is imminent and has been discussed with health care providers. A better understanding of patient characteristics associated with prognostic awareness (PA) is needed to develop interventions aimed at improving it.

Objectives. To identify patient characteristics associated with PA in a PC population.

Methods. The sample comprised 2090 palliative home care patients in Ontario, Canada, assessed using the interRAI Palliative Care Assessment. Independent variables included sociodemographic, cognitive/physical functioning, mood, psychological well-being, and social support. Using cross-sectional data, an adjusted logistic regression model was developed to identify key patient characteristics associated with PA. A multifaceted definition of PA was assumed and represented dichotomously in the model. Multiple imputation was used to address missing data, generating results similar to the complete case analysis.

Results. The PA was higher in patients with: a shorter prognosis (odds ratio [OR] 2.90, 95% confidence interval [CI] 1.93–4.33), increased hours of informal care (OR 1.71, 95% CI 1.15–2.52), less cognitive impairment (OR 1.61, 95% CI 1.14–2.28), and in patients at peace with life (OR 1.79, 95% CI 1.27–2.53). Site differences were observed but do not reflect differences in age, gender, prognosis, or diagnosis.

Conclusion. Some patient characteristics are amenable to clinical intervention to raise PA, such as being at peace, cognitive impairment, and depression. Prognostic communications vary in timing and quality and may underlie our site differences, but further research is required to confirm this. J Pain Symptom Manage 2014;■:■–■.

Key Words

Prognostic awareness, palliative care, interRAI palliative care assessment, predictors of prognostic awareness, psychological well-being

Introduction

Palliative care (PC) philosophy and policy in many countries endorses "open" awareness, where clinicians openly discuss the patient's prognosis.[1,2] This is supported by patients and their families[3,4] and reflects the belief that prognostic knowledge enables patients to make treatment and end-of-life planning decisions, and facilitates acceptance.[5] Moreover, evidence links prognostic awareness (PA) to improved quality of

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life,[5,6] less depression/anxiety,[7–13] and spiritual well-being.[14]

Despite widespread support for "open" awareness, disclosure practices vary significantly by health care provider and geographical location,[15–17] which can account for PA differences, although other factors appear relevant. For example, PA is remarkably stable over time,[18,19] and many patients and caregivers deny or remain uncertain about prognosis even when death is imminent.[10,18,19] This suggests that awareness is influenced by perceptions that may be difficult to change[18] and/or other patient characteristics (e.g., emotional stability and spirituality).[10,20]

Only a few studies have examined the patient characteristics associated with PA.[21] The PA was unrelated to age and gender in some studies,[19] yet others observe lower awareness in older patients,[10,15,22–25] in males,[10] or in females.[10,20,26] Some studies report a positive association between PA and education[23,26,27] and White race.[28] The PA was unrelated to survival time in one study[10] and linked to shorter survival time in another.[1] Some studies have examined psychiatric correlates, with some showing no association with depression,[19] and others showing lower depression levels in PA patients.[7–13] Anxiety was found to reduce the likelihood that patients would request diagnostic or prognostic information.[8] Pain and PA do not appear to be associated,[10,19] but consistent evidence links awareness with improved quality of life.[5,6] Proximity to death has been linked to higher levels of awareness.[12] No association was found between PA and desire to die[10] or caregiver type,[19] although being married and intense social contact have been linked to lower awareness.[10,20] Open discussions about prognosis and participation in end-of-life discussions appear to improve the accuracy of awareness.[29,30] Differences in PA across geographic regions have been reported.[15]

Findings are discrepant and difficult to generalize because of small samples, consideration of only a few characteristics, or examining populations with distinct cultural prognostic disclosure preferences. Most studies also focus on hospices or hospital PC units, rather than the home care sector, which has been growing rapidly in many countries, particularly regarding PC services. Ultimately, PA has been recognized as complex, subtle, and difficult to capture, yet most researchers agree that it warrants further study, particularly the patient characteristics shaping it.[10,20]

The aim of this study was to further our understanding of the patient characteristics associated with PA, and to address limitations in the current research. We use a large palliative home care sample of primarily cancer patients, and examine the association between PA and many patient characteristics, including demographics, prognosis, cognitive function, physical condition/function, mood, psychosocial well-being, and caregiver support. Our data come from the interRAI Palliative Care instrument (interRAI PC), a care planning tool that captures a comprehensive range of health status/symptom measures, including key correlates of PA.[31] The tool was created by interRAI, a collaboration of researchers and clinicians from more than 30 countries (www.interrai.org). It was piloted in six Canadian provinces and is now mandated for use with nearly all Ontario palliative home care clients. It is routinely used in various health care settings across North America, Europe, Australia, Singapore, Taiwan, Israel, and Japan.

Methods

InterRAI™ PC Instrument

A cross-sectional evaluation was done of interRAI PC assessments completed between 2006 and 2012 by trained Care Coordinators.[31] The interRAI PC is designed for adults (18+) with end-of-life needs regardless of care setting, and is intended to inform care planning. The assessment functions more as a semi-structured interview process, where the questions serve as prompts to remind clinicians of issues to discuss one-on-one with patients. The questions are not always asked verbatim or in the order they appear, particularly for sensitive issues such as PA, spirituality, and desire for death. Instead, assessors engage the patient in a conversation about their illness, and listen to their responses to assess the patient's understanding/expectations. Assessors are trained on how to approach sensitive issues and what to listen for, to ensure some degree of consistency in the conversations. Caregivers are typically present at the assessments, and this is often preferred by all parties. Assessors may look to caregivers to corroborate statements made by patients. They also review medical records and speak to attending physicians to ensure an accurate assessment.

Study Sample

Pilot data were collected on PC patients assessed for home care services within six regional jurisdictions in Ontario, Canada. Patients were classified as palliative if they were no longer responsive to curative treatment, considered to be dying, and the primary goal of care was to alleviate distressing symptoms in the last stage of illness.[32]

The PA item on the assessment pertains to patients with a prognosis less than six months. Moreover, patients with severe cognitive impairment may have neurodegeneration, which can interfere with their

emotional disposition and ability to express PA.[33] Therefore, patients were excluded if their prognosis was greater than six months or if they exhibited severe cognitive impairment (i.e., Cognitive Performance Score [CPS] higher than 4; see "Measures" section below).

Measures

The dependent variable, PA, represents the assessor's response to the interRAI PC question "Verbalizes awareness of terminal prognosis of less than 6 months to live (do not probe): 0—No or not applicable and 1—Yes."[31] To answer this, assessors typically begin with the open-ended question: "I see that you are seeing Dr. … What has he/she told you about your illness?" The assessor determines if the patient's response shows awareness that their illness is terminal. If not, a further question is often asked: "Have you discussed the next few months with Dr. …, or the need for further treatments?" The aim is to record whether the patient is aware of the severity of their illness, and is only completed if the patient makes such statements. The PA, as operationalized in the interRAI PC assessment process, is best viewed as a multifaceted concept, with statements indicating awareness of terminal illness, shortened life expectancy, or palliative (noncurative) treatments all being taken as an indication of PA.

Patient characteristics were selected based on prior literature and the availability of items in the interRAI PC. Common correlates of awareness include age, gender, education, psychiatric conditions, prognosis, site/region, and open discussions (see Introduction section). The interRAI PC includes these items (except education and prognostic communications) and many others relevant to PA. It contains embedded scales for measuring functional ability and impairment. The Depression Rating Scale (DRS) is assessor-rated, summative across seven items, and ranges from zero to 14. It has been validated in a PC population[34] and a score of three or higher has been shown to be predictive of a clinically confirmed depression diagnosis.[35,36] The CPS ranges from zero (cognitively intact) to six (very severe impairment), and has been validated against the Mini-Mental State Examination.[37] Functional performance was measured using the Activities of Daily Living Self-Performance Hierarchy Scale (ADL-H), which categorizes four ADLs on a scale ranging from zero (independence) to six (total dependence in late-loss ADLs),[38] with a score of two being a conventionally used cutoff indicating that limited assistance is required for at least one ADL. Pain was assessed using a four-point pain scale ranging from zero (no pain) to three (excruciating daily pain), with a cutoff of two identifying daily pain. The pain scale has been validated against the Visual Analogue Scale.[39] Health instability and illness severity were measured using the Changes in Health, End-stage disease and Signs and Symptoms (CHESS) scale, which identifies individuals at risk of serious health decline/mortality.[40] The CHESS scores range from zero to five (highest health instability).

The interRAI PC also includes items that may impact PA directly or through psychological correlates, including spiritual well-being[14] and desire for death.[41] Four self-report binary measures are available: being at peace with life, finding life meaningful, finding guidance in religion/spirituality, and desire for death. Assessors listen carefully to patient responses to accurately assess these constructs. For example, a patient expressing excitement about upcoming events (e.g., gardening and weddings) suggests that they find life meaningful and do not want to die.

Statistical Analysis

A (relaxed) alpha level of 0.30 was used for the χ^2 significance tests to identify the initial list of independent variables to guard against the omission of potentially important variables. Table 1 lists the variables considered for model inclusion, with some being summative measures (number of comorbidities and gastrointestinal disorders) or condition on the presence of concerns (caregiver distress). All variables were categorical, with the categories determined by examining logit plots and distributional properties.

A multivariate binary logistic regression model was employed using PA as the dependent and interRAI functional indicators and other significant items as independent variables. Multicollinearity was assessed using polychoric correlations because these are preferred as a measure of association for ordinal/categorical data.[42,43] A cutoff of 0.40 was used to identify variable pairs where elimination of one item was required to avoid mulitcollinearity problems. Correlations exceeded the cutoff for the following variables: prognosis with ADL-H and appetite problems, CPS with ADL-H, ADL-H with informal care hours, and items on finding life meaningful and being at peace with life.

Prognosis was kept in the model, and appetite problems and ADL-H were eliminated because prognosis showed a stronger relationship with awareness. This allowed retaining CPS and informal care hours because multicollinearity was no longer a concern. The item measuring "at peace with life" was retained because it showed the stronger relationship with awareness.

Missing data for most items were lower than 3% (Table 1), although restricting the analysis to patients

Table 1
Item Subgroups Stratified by Prognostic Awareness

Item	Categories	Missing, *n* (%)[a]	All Patients, *N* = 2090, *n* (%)[b]	Aware, *N* = 1148, *n* (%)	Not Aware, *N* = 942,[c] *n* (%)	*P*-value (for χ^2)	Unadjusted OR (95% CI)[d]
Age (y)	18–64	6 (0.3)	685 (32.9)	378 (33.0)	307 (32.7)	0.99	0.9 (0.8–1.4)
	65–74		530 (25.4)	290 (25.3)	240 (25.5)		1.0 (0.7–1.4)
	75–84		615 (29.5)	337 (29.5)	278 (29.6)		1.0 (0.8–1.4)
	85+		254 (12.2)	139 (12.1)	115 (12.1)		Reference
Gender	Male	14 (0.7)	1002 (48.3)	544 (47.8)	458 (48.8)	0.67	1.1 (0.9–1.2)
	Female		1074 (51.7)	593 (52.2)	481 (51.2)		Reference
Marital status	Married or has partner	70 (3.4)	1261 (62.4)	683 (61.3)	578 (63.2)	0.23	1.1 (0.9–1.3)
	No partner		759 (37.6)	432 (38.7)	327 (35.8)		Reference
Site,[e] Windsor	1	0 (0.0)	104 (5.0)	46 (4.0)	58 (6.2)	<0.0001	1.4 (0.8–2.3)
	2		1144 (54.7)	635 (55.3)	509 (54.0)		2.2 (1.5–3.1)
	3		369 (17.7)	185 (16.1)	184 (19.5)		1.7 (1.2–2.6)
	4		246 (11.8)	184 (16.0)	62 (6.6)		5.2 (3.3–8.2)
	5		90 (4.3)	48 (4.2)	42 (4.5)		2.0 (1.1–3.4)
	6		137 (6.6)	50 (4.4)	87 (9.2)		Reference
Number of comorbidities[f]	5+	0 (0.0)	21 (1.0)	7 (0.6)	14 (1.5)	0.06	0.4 (0.2–1.0)
	3–4		301 (14.4)	176 (15.3)	125 (13.3)		1.2 (0.9–1.5)
	≤2		1768 (84.6)	965 (84.1)	803 (85.2)		Reference
Prognosis	Death <6 wk	0 (0.0)	321 (15.4)	228 (19.9)	93 (9.9)	<0.0001	2.3 (1.8–2.9)
	≥6 wk and <6 mo		1769 (84.6)	920 (80.1)	849 (90.1)		Reference
CHESS	3+ (Moderate-high instability)	46 (2.2)	1789 (87.5)	984 (87.9)	805 (87.1)	0.62	1.1 (0.8–1.4)
	<3 (No-low instability)		255 (12.5)	136 (12.1)	119 (12.9)		Reference
Pain Scale	Moderate-severe (2+)	14 (0.7)	1560 (75.1)	847 (74.4)	713 (76.0)	0.41	0.9 (0.8–1.1)
	None-mild		516 (24.9)	291 (25.6)	225 (24.0)		Reference
CPS	<2 (None-mild)	0 (0.0)	1669 (79.9)	957 (83.4)	712 (75.6)	<0.0001	1.6 (1.3–2.0)
	2+ (Moderate-severe)		421 (20.1)	191 (16.6)	230 (24.4)		Reference
ADL SHS	Independent	26 (1.2)	1063 (51.5)	607 (53.5)	456 (49.0)	0.05	1.2 (1.0–1.4)
	Limited-extensive (2+)		1001 (48.5)	527 (46.5)	474 (51.0)		Reference
DRS	None-minor	50 (2.4)	1778 (87.2)	991 (88.8)	787 (85.2)	0.01	1.4 (1.1–1.8)
	Depressive symptom (3+)		262 (12.8)	125 (11.2)	137 (14.8)		Reference
Desire for death	Yes	722 (34.5)	101 (7.4)	75 (8.7)	26 (5.2)	0.02	1.7 (1.1–2.7)
	No		1267 (92.6)	791 (91.3)	476 (94.8)		Reference
Sleep issue (insomnia)	Moderate-severe	53 (2.5)	561 (27.5)	318 (28.4)	243 (26.4)	0.31	1.1 (0.9–1.3)
	None-mild		1476 (72.5)	800 (71.6)	676 (73.6)		Reference
Sleep issue (too much)	None-mild	59 (2.8)	1454 (71.6)	812 (73.0)	642 (69.9)	0.11	1.2 (1.0–1.4)
	Moderate-severe		577 (28.4)	300 (27.0)	277 (30.1)		Reference
Appetite	Poor	36 (1.7)	636 (31.0)	377 (33.6)	259 (27.8)	0.005	1.3 (1.2–1.6)
	Good		1418 (69.0)	745 (66.4)	673 (72.2)		Reference
At peace with life	Yes	680 (32.5)	1160 (82.3)	706 (84.4)	454 (79.1)	0.01	1.5 (1.1–1.9)
	No		250 (17.7)	130 (15.6)	120 (20.9)		Reference
Finds life meaningful	No	609 (29.1)	199 (13.4)	108 (12.4)	91 (14.9)	0.17	1.2 (0.9–1.7)
	Yes		1282 (86.6)	763 (87.6)	519 (85.1)		Reference
Guided by religion	No	705 (33.7)	366 (26.4)	217 (27.5)	149 (25.0)	0.30	1.1 (0.9–1.5)
	Yes		1019 (73.6)	572 (72.5)	447 (75.0)		Reference
Hours of informal care	>48 h	48 (2.4)	373 (18.3)	241 (21.5)	132 (14.3)	<0.0001	1.7 (1.3–2.2)
	>24 h and ≤48 h		467 (22.9)	256 (22.8)	211 (22.9)		0.9 (0.7–1.1)
	≤24 h (in last 3 d)		1202 (58.9)	624 (55.7)	578 (62.8)		Reference

Dyspnea	Present at rest	13 (0.6)	412 (19.8)	253 (22.2)	159 (17.0)	0.03	1.4 (1.1–1.8)
	Present–normal activity		599 (28.8)	323 (28.3)	276 (29.5)		1.0 (0.8–1.3)
	Present, moderate activity		434 (20.9)	227 (19.9)	207 (22.1)		1.0 (0.7–1.2)
	Absent		632 (30.4)	338 (29.6)	294 (31.1)		Reference
Gastrointestinal symptoms	Moderate-severe	83 (4.0)	1056 (52.6)	593 (53.9)	463 (51.1)	0.20	1.1 (0.9–1.3)
	None-mild		951 (47.4)	507 (46.1)	444 (48.9)		Reference
Caregiver distress	Signs of distress	58 (2.8)	618 (30.4)	326 (29.2)	292 (32.0)	0.17	1.2 (1.0–1.4)
	No signs of distress		1414 (69.6)	792 (70.8)	622 (68.0)		Reference

OR = odds ratio; CI = confidence interval; CHESS = Change in Health, End-Stage and Disease Symptoms and Signs; CPS = Cognitive Performance Scale; ADL SHS = Activities of Daily Living Self-Performance Hierarchy Scale; DRS = Depression Rating Scale.

[a]Expressed as the number missing for this item divided by the number of clients with a non-missing prognostic awareness (2090 of the 2425 clients in the total sample), multiplied by 100.

[b]Subgroup totals are the total sample ($n = 2417$) less clients where prognostic awareness and/or item was missing.

[c]Corresponds to a prognostic awareness prevalence of 54.9% $(1148/[1148 + 942] \times 100)$.

[d]95% CIs straddling 1.0 are not statistically significant. Odds ratios represent odds of being aware of prognosis.

[e]All six sites are located in Ontario, Canada; site names are not shown to protect patient confidentiality.

[f]Includes primary diagnosis.

having a response for all variables (complete case analysis) reduces the sample from 2425 to 1020, a reduction of 58%. We believe that our missing data reflect a random pattern. Multiple imputation is recommended for this pattern because it has been shown to produce unbiased results with correct standard errors.[44–47] Therefore, we performed multiple imputation and provide these results alongside the complete case analysis.[45] This involved multiple logistic regression runs (one for each imputation), using backward elimination and a significance level of 0.05 for retaining variables in the model. Factors were considered significant in the multiple imputations if they were selected in at least 50% of the regression runs. Multiple imputation used continuous-based imputation with rounding,[44] and the results for 50 imputations were pooled using normalizing transformations.[48] Imputations included the dependent variable,[49] and the independent variables meeting the relaxed *P*-value and not eliminated because of multicollinearity.

We assessed the goodness-of-fit of the model using measures of both discrimination and calibration.[50,51] The *c* statistic was chosen as the measure of discrimination, with a value of $0.7 \leq c < 0.80$ considered acceptable. The Hosmer and Lemeshow statistic was chosen for calibration, with a small value and large *P*-value considered acceptable.[50]

The SAS, version 9.2 (SAS Institute, Inc., Cary, NC) was used for all of the statistical analyses (www.sas.com). The study was approved by the Office of Research Ethics at the University of Waterloo. The University of Waterloo manages and controls access to the data used in this study.

Results

Two-thirds of the sample was older than 65 years, the sample was evenly distributed by gender (48.3% male), and 62.4% were married (Table 1). About 55% of the patients were aware of their prognosis. About 12% of the sample exhibited depressive symptoms, representing patients with a DRS score of 3+.[35] Most (85%) patients had an estimated prognosis of between six weeks and six months. A total of 87% of the patients had a CHESS score of 3+, three-quarters experienced daily pain, and about half had at least moderate functional impairment. Around 20% of the patients had a CPS score of 2 or 3 (patients with 4+ were eliminated), 30% indicated their caregivers were distressed, and more than 80% were at peace with life and found life meaningful. Most (86%) patients had a primary diagnosis of cancer.

Bivariate analyses showed that being unaware of one's prognosis was associated with a longer

Table 2
Factors Associated With Prognostic Awareness: Comparison of Complete Case and Multiple Imputation Analyses

	Complete Case Analysis ($N=1020$)	Multiple Imputation ($N=2425$)
Independent Variable	Adjusted OR (95% CI)	Pooled Adjusted ORs (Pooled 95% CI)
Prognosis		
<Six weeks	2.90 (1.93–0.33)	2.26 (1.72–2.96)
≥ Six weeks and <Six months	Reference	Reference
At peace with life		
Yes	1.79 (1.27–2.53)	1.47 (1.13–1.92)
No	Reference	Reference
Informal care hours		
>48 hours	1.71 (1.15–2.52)	1.62 (1.28–2.06)
>24 and ≤48 hours	0.88 (0.64–1.22)	1.06 (0.86–1.29)
≤24 hours (in last three days)	Reference	Reference
Cognitive impairment		
CPS <2 (None-mild)	1.61 (1.14–2.28)	1.76 (1.38–2.23)
CPS 2+ (Moderate-severe)	Reference	Reference
Site		
1	0.92 (0.44–1.91)	1.23 (0.74–2.06)
2	1.74 (1.03–2.96)	1.71 (1.14–2.58)
3	1.44 (0.81–2.55)	1.60 (1.03–2.51)
4	6.93 (3.44–13.93)	4.05 (2.67–6.16)
5	1.98 (0.74–5.28)	1.40 (0.84–2.31)
6	Reference	Reference
Goodness of fit		
c Statistic	0.67	0.64 (0.63–0.65)[a]
Hosmer and Lemeshow		
χ^2	4.39	6.73 (2.5–13.1)[a]
P	0.73	0.56 (0.09–0.96)[a]
df	8	8 (7–8)[a]

OR = odds ratio; CI = confidence interval; CPS = cognitive performance scale; df = degrees of freedom.
[a]Mean (minimum–maximum).

prognosis, mild-to-moderate cognitive impairment, depressive symptoms, fewer appetite problems, less dyspnea, no desire to die, not being at peace with life, and less informal care. The PA levels also differed significantly by site. No significant associations were observed with the demographic variables (age, gender, and marital status), pain, CHESS, ADL-H, sleep issues, number of comorbidities, gastrointestinal problems, caregiver distress, finding life meaningful, and seeking guidance from religion/spirituality.

The complete case and multiple imputation methods selected the same five items into the model and were similar in the relative strength of item associations with PA (Table 2). Prognosis had the strongest association with PA, and the other significant items included being at peace with life, informal care hours, cognitive impairment, and site. The *c* statistic was below the 0.70 cutoff for the complete case and multiple imputation methods. The Hosmer and Lemeshow statistic for the complete case model was relatively small, with a large *P*-value (4.12; $P=0.77$), indicating acceptable model fit.

Discussion

About 45% of our sample was unaware of their prognosis. Recent evidence suggests that as high as 75% of patients may be unaware of their prognosis,[21] as a result of overly optimistic prognoses, misinterpretation of physician information, reluctance to discuss prognosis, and denial/avoidance strategies.[52] These reasons may explain our low awareness levels, but the care setting also may be important. Our patients were home care clients who were classified as PC patients, but may not have been receiving palliative services at assessment time. Also, patients in more intensive PC settings (e.g., hospital PC units and residential hospices) must be acutely ill to qualify for these services in Ontario, thus they may perceive a poorer prognosis compared with home care patients. Some assessors in our study also indicated that there is considerable variability in prognostic communications, and that some patients had either poor or no prognostic communication with their physician before the assessment (personal communications, K. F. with Care Coordinators, May–June, 2014). Other studies show that physicians vary significantly regarding their intentions for prognostic communications[16] and often delay prognostic discussions until patients' circumstances become dire or patients/families request information.[52–55] Variation in PC services in Ontario has been attributed to regional differences in care protocols and resources, practice variation among the providers in the care continuum, and lack of service integration across the continuum.[56] Perhaps, legislation would help to standardize and coordinate PC services, and clarify who is responsible for discussing

prognosis with patients, and the timing and content of the discussions. Increased training for providers also may help to raise their comfort level in discussing prognosis, ensure that information is consistently conveyed and usable by patients, and enable providers to accurately assess patient understanding.[55]

Although our patients may have been less acutely ill than those in more intensive care settings, prognostic variation existed within the sample, with higher awareness among patients having a shorter prognosis, consistent with other studies.[12,19,52] We found that 71% of the patients with a prognosis of less than six weeks were compared with 52% of the patients with a prognosis of more than six weeks. Awareness levels in our study still appear low for patients within a few weeks of dying. For example, Hinton[19] found that only a few individuals in the final weeks of life showed prognostic disavowal, and Chochinov et al[10] found that this group represented about 10% of their sample. However, the methods used to assess/express awareness vary across studies,[21] and these can cause important differences in reported levels of awareness. We used a binary item to capture awareness, whereas others express levels of awareness. For example, in the study by Chochinov et al,[10] 10% were completely unaware and 17% were partially aware; a binary classification could suggest that 27% were unaware, which is closer to the 29% we observed (for prognosis less than six weeks). Currently, the PA measures vary across studies, making it difficult to compare them on the proportion showing PA. More studies on the utility/merit of different PA measures are required to develop a recommended "gold standard." However, differences in how PA is conceptualized do not appear to impact findings on the patient characteristics shaping it, which is the main purpose of our study.[21]

The relationship between awareness and prognosis bears further consideration too because prognosis is a surrogate for changes occurring as death approaches. Prognosis was more significant than other symptoms (e.g., depressive symptoms and dyspnea), perhaps capturing a collective effect shaping PA beyond the individual symptoms. The variables eliminated because of multicollinearity with prognosis may suggest effects underlying it. We re-ran the complete case regression, replacing prognosis with the two variables highly correlated with it (appetite problems and ADL-H). Appetite problems but not ADL-H were significant, and the other effects remained the same, suggesting that appetite problems may be among the important changes that occur as death approaches. Appetite problems are common in PC patients;[57] but in the one study we know of exploring the link with awareness, PA patients had fewer appetite problems.[1] Perhaps shorter prognoses and potential underlying effects, such as appetite loss, reduce quality of life,[58] which in turn raises awareness.[1] More research is required to understand the interrelationships and identify underlying mechanisms shaping PA.

We also found that PA increased as informal care hours become intensive. This may reflect the psychological impact of losing independence or patients' seeing themselves as a burden. It does not appear to reflect caregiver distress, however; although caregiver distress is higher in those providing more care, removing informal care hours from the model results in the four other variables remaining significant, with caregiver distress still having no effect. Perhaps, the type of contact and not distress impacts PA. For example, Chochinov et al[10] found that intense family contact was linked to lower PA, and suggested that family members may collude to deny the prognosis of a loved one. Such collusion may be more difficult to maintain when contact progresses beyond social visitations to assume more intensive caregiving roles. The implications of these findings are that the caregiving role may shape PA, and that the intensity of caregiving may be an indicator of PA. More research is needed to understand these complex relationships.

We found that being at peace with life also was associated with PA. Other evidence suggests that PA facilitates psychological adjustment, including less depression/anxiety,[7–13] spiritual well-being,[14] and better emotional quality of life.[5,6] Interestingly, depressive symptoms were not associated with PA in our model, despite associations reported in the literature and the significant bivariate relationship between the DRS score and PA (Table 1). Perhaps being at peace mediates the relationship between depressive symptoms and PA. We tested this using the methodology of Frazier et al,[59] and found that the "at peace" variable met all four mediation conditions, namely significant relationships existed between PA and the DRS ($P = 0.02$) and being at peace ($P = 0.008$), a significant relationship existed between the DRS and being at peace ($P < 0.0001$), and the relationship between the DRS and awareness was significantly reduced once the at peace variable entered the model (z statistic for mediation effect $= -2.45$, > -1.96). These findings suggest that being at peace may directly and indirectly (by mediating depression) shape PA. It also suggests that methods that assist patients in achieving a peaceful state are important, including psychotherapeutic interventions such as Outlook[60] and Dignity Therapy,[61] which have shown promise in helping patients achieve a state of peace.

Site also was associated with differences in PA. Most studies involve patients from a single facility, whereas ours included patients from six sites, which introduces other variables affecting PA such as client

characteristics or methods/styles of prognostic communication. Further examination shows that the characteristics including age, gender, pain, and primary diagnosis do not account for site differences. Costantini et al[15] concluded that the lower prognostic disclosure levels observed in remote Italian regions reflected higher degrees of paternalism. This is an unlikely explanation of our site differences, however, because the two sites with higher awareness contrast one another, with one being a large metropolitan center and the other a small northern/remote community. Our site differences may reflect variation in the PC care services delivered across Ontario, which could be addressed in part by introducing legislation to guide service delivery. However, variation will remain even with legislation because patients and providers differ greatly on their preferences for the amount and timing of prognostic information, although both believe the information is important.[55]

Several limitations should be considered in interpreting our results. First, our study is cross-sectional, which means directionality remains uncertain and changes in PA over time are not analyzed. Prognosis is subject to error and often is a moving target,[21] thus awareness of it will have similar properties. Longitudinal research is needed to understand temporal changes in PA and what drives them. Second, our measure of PA pertains to those with a prognosis of less than six months, thus the results cannot be generalized to patients with a longer prognosis. Third, patients often show ambivalence regarding awareness, or express awareness differently to different people, with disclosure being a function of the recipient's attitude to listening and openness to discussing prognosis and patient stability.[62] This suggests that complete reliability in measuring awareness is unlikely,[19] with the accuracy of both clinician- and patient-reported measures being questioned.[21] However, the impact on studies like ours may be minimal because the correlates of PA appear to be stable across measures.[21] Finally, we have no information on prognostic communications between patients and providers, yet this will shape awareness and may account for the significance of site in our model. A recent study found that only 16.5% of the patients had PA despite 70% of their physicians indicating that they discussed prognosis, calling into question the quality of prognostic communications.[52] Other research cites discrepancies between physicians and patients regarding what was said about prognosis, perceptions about information needs, and levels of understanding.[17]

Conclusion

Our results are consistent with the frequent finding that a significant proportion of patients are unaware of their impending death even when it is imminent. We examined a comprehensive range of factors, available in the interRAI PC assessment, and found that awareness increases as cognitive impairment declines, prognosis becomes shorter, informal care hours increase, and the patient is at peace with life. Although longitudinal research is required to confirm and further understand these associations, our results offer preliminary evidence of modifiable factors that could be the focus of interventions aimed at raising PA. For example, being at peace is linked with acceptance of death and a sense of completion, both recognized as important in preparing for end of life by patients, families, caregivers and clinicians.[63] Psychotherapeutic interventions such as Outlook[60] and Dignity Therapy[61] show promise in helping patients achieve these attributes. Cognitive impairment and depression may be amenable to treatment, with various nonpharmacologic and pharmacologic interventions having been shown to be effective in some patient groups.[64–66] These interventions can be implemented by many health care providers in the care continuum.

We also found site differences in PA, which may reflect variation in prognostic communications. Although legislation and training can reduce this variation, patient and provider differences will continue to exist. Patients also may not understand or use prognostic information the way it was intended by providers.[55] Techniques such as the "teach-back" or "show me" method,[67] and repeated checking with patients to make sure prognostic information is still desired and understood,[68] can help bridge this gap.

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